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Requests for euthanasia or physician-assisted suicide from older persons who do not have a severe disease: an interview study

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ABSTRACT

Objective. To determine how often requests are made for euthanasia and physician-assisted suicide (EAS) in the absence of severe disease and how such requests are dealt with in medical practice in The Netherlands.

Method. Retrospective interview study. Participants: 125 general practitioners (GPs), 77 nursing home physicians (NHPs), and 208 clinical specialists.

Results. In The Netherlands, each year approximately 400 people request EAS, because they are 'weary of life'. Thirty per cent of all physicians have at some time received an explicit request for EAS in the absence of severe disease; 3% of all physicians had granted a request for EAS in such a case. Most requests for EAS to GPs in the absence of severe disease ($n=29$) were made by single people aged 80 years and over. While their problems were most frequently of a social nature, 79% had one or more non-severe illnesses. Most GPs refused the request; half of them proposed an alternative treatment, which the patient often refused. Nineteen people who did not receive any treatment persisted in their wish to die; the request for EAS from 5 out of 10 patients who received one or more types of treatment was withdrawn or became less explicit.

Conclusions. Most physicians in The Netherlands refuse requests for EAS in the absence of severe disease. Most patients persist in their request. In an ageing population more research is needed to provide physicians with practical interventions to prevent suicide and to make life bearable and satisfactory for elderly people who wish to die.

INTRODUCTION

Life expectancy is increasing in industrialized countries, and in most Western countries 50% of the population can already expect to survive to the age of 80 years (Kinsella, 1996). Old age is often accompanied by disabilities and a reduced quality of life. Some elderly people consider this to be unacceptable and develop a wish to die. There are several factors associated with increasing age that are also associated with a wish to die, such as depression, not being married, poor self-rated health, disability, pain, hearing impairment, visual impairment and living in a nursing home (Jorm *et al*. 1995).

Whereas most people will think suicide too drastic a measure, their only alternative is to wait until time fulfils their wish to die. In The Netherlands, however, where there is increasing openness about requesting assistance with dying

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from a physician, elderly people may consider this a third option. This has resulted in a debate about the ethics of euthanasia and physician-assisted suicide (EAS) for elderly people who wish to die but do not suffer from a severe physical or psychiatric disease. This debate has been further stimulated by a test case in The Netherlands: a general practitioner (GP) who assisted an elderly and ailing, but not severely ill, patient to commit suicide was prosecuted. The GP thought he had met the requirements for prudent practice: a well-considered voluntary request for EAS from the patient, unbearable and hopeless suffering, no treatment alternatives, consulting another physician, and reporting the case to the authorities. In first instance the physician was acquitted, but on appeal and before the Supreme Court he was found guilty without imposition of a punishment. An important argument in the verdict of the Supreme Court was that dealing with a wish to die in the absence of a severe disease does not fall within the medical domain of a physician. The physician should have consulted an expert, although it remained unclear who should be considered an expert in this field (Dutch Supreme Court, 2003).

We performed this study several months before the verdict of the Supreme Court was announced. The aim was to estimate the incidence of requests for EAS in the absence of a severe disease, to get a general insight in the characteristics and reasons of the patients who make such requests, and to learn more about how physicians, and in particular GPs, deal with such requests.

METHOD

Definitions

Euthanasia is defined as the administration of drugs with the explicit intention of ending the patient's life at his/her explicit request. Physician-assisted suicide is defined as the prescription or supply of drugs with the explicit intention to enable the patient to end his/her own life.

Design and study population

This study was performed in 2002 as part of a large-scale study of medical decision-making at the end of life, commissioned by the Minister of Health, Welfare and Sports and the Minister of Justice, and consisted of retrospective semi-structured interviews with a random sample of nursing home physicians (NHPs) ($n=77$), GPs ($n=125$) and clinical specialists (cardiologists, surgeons and specialists in internal medicine, pulmonology and neurology) ($n=208$) (Onwuteaka-Philipsen *et al.* 2003; van der Wal *et al.* 2003). To meet the criteria for inclusion in this study, these physicians had to be practising in their registered speciality in the same nursing home, practice or hospital for the past 2 years. Of the 482 physicians who met the selection criteria, 72 were unwilling to participate (15%), mostly due to a lack of time.

Measuring instruments and analysis

To enable the physicians to feel free to speak about potentially illegal acts, anonymity was guaranteed by the researchers. Moreover, the Ministry of Justice guaranteed that it would not initiate any judicial inquiries based on the information collected in this study.

The interviews were conducted by physicians who had received specific training for this study.

The interviews had an average duration of $1\frac{1}{2}-2$ hours. Clinical specialists, NHPs and GPs were asked about the main reasons for the requests for EAS that they had received: a physical disease, a psychiatric disease or being weary of life. Physicians knew before the interview what the subject of the interview would be, and they were asked to make an overview of the frequencies of requests for EAS they had received. This method was chosen to obtain estimates of the number of requests for EAS in The Netherlands. Furthermore, GPs and NHPs were asked about the most recent requests for EAS in the absence of a severe disease. The interviewers explained our definition of this to the respondent as follows: 'It does occur that patients do not want to continue living, whereas they do not have a severe physical or psychiatric disease. Sometimes this is referred to as suffering from life, being through with life or being tired of living. It is possible that the patient has health problems – e.g. a chronic illness or ailments of old age – it is also possible that the patient is healthy.' After this explanation the interviewer asked whether it had ever occurred that a patient who did not suffer from a physical or psychiatric disease had explicitly requested the respondent for EAS. In case of doubt about the definition

Table 1. *Number of patients who explicitly requested euthanasia and physician-assisted suicide (EAS) in 2000 and 2001 and estimated annual number in The Netherlands, according to specialty and to the main reason for the request: a physical disease, a psychiatric disease or being weary of life*

	General practitioners ($n=125$)	Clinical specialists ($n=208$)*	Nursing-home physicians ($n=77$)	Total (95% CI) ($n=410$)*
Respondents: no. of patients who requested EAS in 2000 and 2001	227	327	81	635
Main reason for the request†				
Physical disease	91·2%	97·4%	81·0%	92·6%
Psychiatric disease	3·5%	0·9%	7·5%	2·9%
Weary of life	5·3%	1·7%	11·4%	4·5%
The Netherlands: estimated annual no. of patients who requested EAS‡	6375	2900	425	9700 (8800–10500)
Main reason for the request				
Physical disease	5800	2825	350	9000 (8125–9875)
Psychiatric disease	225	25	25	275 (125–450)
Weary of life	325	50	50	425 (225–650)

* One missing case.
† The percentages for clinical specialists and the total are weighted for speciality of the physician.
‡ The estimates for the Netherlands were weighted and rounded.

of 'severe disease', the interviewer had more extensive information, e.g. someone with a clinical depression was considered to have a severe illness, while someone with only depressed symptoms was not. Only GPs were asked to describe a request in detail. GPs were selected because we assumed their patients would more often than the patients of other physicians meet our definition of not having a severe disease. The GPs were asked to describe the most recent case in which a patient requested EAS in the absence of severe disease. If they had ever granted such a request they were asked to describe the most recently granted request ($n=4$); if not, they described the most recent request that was not granted ($n=28$). Of the 28 requests not granted, three were not included in the analysis because the patients appeared to have a severe psychiatric disease.

The interviews consisted mainly of open-ended questions. Most questions did have pre-structured answering categories, but these were not read out to the respondent. These categories were given to the interviewer to bring nuance to answers that could otherwise have been missed by them. For some questions, the answer categories were made visible to the respondent with cards. For example, the question about important reasons for the request for EAS was because we wanted to know whether each of the reasons derived from previous research played an important role or not. Moreover, to develop an understanding of the personal situation of the patient there was also space with each question to describe a more extensive answer. During the interviews, physicians could check medical records of cases they were discussing. Due to the peculiarity of requests for EAS in the absence of severe disease, most physicians remembered these cases in detail.

To calculate estimates that were representative for The Netherlands the numbers of (requests for) EAS were weighted for the speciality of the physician and corrected for the 5% of the deaths covered by other physicians than the seven types studied.

RESULTS

Requests: frequencies, patient characteristics and reasons

Table 1 shows the annual number of requests for EAS and the main reasons. Of all the explicit requests that were primarily based on 'physical disease', approximately 42% were granted (approx. 3800 out of 9000). Explicit requests that were primarily based on a 'psychiatric disease' were never granted, and explicit requests based on being 'weary of life' were almost never granted (approx. 1%).

Table 2. *Characteristics of patients who made a request to their general practitioner for euthanasia and physician-assisted suicide (EAS) in the absence of a severe disease (n = 29)**

	n	%		*n*	%
Age at first request (years)			Problems†‡		
60–69	3	10	Physical (lack of appetite 7, sleeping disorder 6, pain 2)	6	22
70–79	9	31	Communicative (blind 7, deaf 5, unable to write 5)	6	22
80–89	11	38	Mobility (tiredness 9, dependent for ADL 7, unable to walk 5)	6	22
90–97	6	21	Mental (melancholy 12, unable to cope 11, depressed 10)	11	41
Gender			Societal (lack of (leisure) activities 19, no valuable role in life 15, lack of social network 12)	16	59
Male	13	45	One or more non-severe illnesses		
Female	16	55	Yes	23	79
Partner			No	6	21
Yes	7	24	Care evaluation		
No	22	76	Adequate	21	72
Children			Inadequate	7	24
Good contact	12	41	Unknown	1	3
Low quality/no contact	7	24	Ever attempted suicide		
Unknown contact	2	7	Yes	1	3
No children	7	24	No	27	93
Unknown	1	3	Unknown	1	3
Health status			Competent to overlook own situation and adequately make decisions about it†		
Good	9	31	Yes	21	78
Reasonable	14	48	Not fully	6	22
Moderate	5	17	Received care†		
Poor	1	3	Umbrella care	15	56
Under care of this GP for			Housekeeping	12	44
< 1 year	1	3	Residential home	7	26
1–5 years	5	17	District nursing care	4	15
> 5 years	23	79	Spiritual care	3	11
Personality traits			Voluntary services	3	11
Taken stock of life	25	86	Home care	2	7
Intellectual/educated	21	72	Private nursing	1	4
Become isolated	17	59			
Difficulty with dependence	17	59			
Proud of own achievements in life	16	55			
Difficulty with adjusting to old age	16	55			
Hopeless and despondent	13	45			
Difficulty with loss of standing	11	38			
Difficulty with death of partner	8	28			
Fear of loss of competence	8	28			
Simple-minded	6	21			
Financial problems	0	0			

* Requests granted and not granted.
† Two missing cases.
‡ For 33 items in five areas the physician assessed on a scale from 1 to 5 the extent of the patient's problems at the time of the first explicit request for EAS. For example, the definition of physical problems was if the patient had considerable problems (score 4 or 5) with two or more items in that area. For each area the three items that were most frequently assessed with a score of 4 or 5 are shown, together with the number of patients who scored 4 or 5 on that item. In this way all problems were assessed.

Thirty per cent of the GPs and NHPs had at least once received an explicit request for EAS from a patient who did not suffer from a severe physical or psychiatric disease; 11% had received an explicit request in the past 2 years. Three per cent of all GPs had granted such a request, but not in the past 2 years. None of the NHPs had ever granted such a request (data not shown).

The average age of the patients at the time of their first request was 81 years (Table 2). None of the patients had a severe disease, but 79% had one or more non-severe illnesses, such as stable status after cancer or a heart condition (11), visual or hearing impairment (7/5), decreased mobility (5), arthritis (3), and intestinal disorders (3). In spite of this, the physicians described their health status most frequently as reasonable, and their problems were more often of a social or mental nature. In 72% of the cases the physician stated that the patient was receiving adequate care.

Table 3. *Reasons for the request for euthanasia and physician-assisted suicide (EAS) in the absence of a severe disease (n = 29)**

	All reasons		Most important reason†	
	n	%	*n*	%
Through with life	16	55	9	32
Physical decline	16	55	4	14
Tired of living	14	48	1	4
No purpose in life	12	41	0	0
Melancholy/depressed	11	38	3	11
Loneliness	11	38	2	7
Dependence	9	31	1	4
Suffering from life	8	28	1	4
Deterioration/loss of dignity/loss of status	6	21	1	4
Not wanting to be a burden on family anymore	5	17	0	0
Pain	4	14	2	7
Cognitive decline	4	14	0	0
Death of a relative	3	10	2	7
Unable to live independently	3	10	0	0
Other	4	14	2	7

* Requests granted and not granted. More than one answer was possible.

† One missing case.

Table 4. *Treatments considered and provided by the GP and whether the request for euthanasia and physician-assisted suicide (EAS) was withdrawn or became less explicit in time (n = 29)**

Treatment	Treatment considered by the physician†	Treatment provided	Request was withdrawn or became less explicit in time
No	15‡	19‡	0
Yes	14	10	5
Antidepressant medication	5	4	2
Psychiatric/psychological§	6	2	1
Psychosocial§	7	3	2
Analgesic medication	2	2	1
Other medical	4	3	2

* Requests granted and not granted.

† Possible treatment considered by the physician after the explicit request for EAS, that was not provided before the request.

‡ Four patients refused all treatment, so in 15 cases no treatment was considered and in 19 cases no treatment was provided.

§ Psychiatric/psychological treatment = treatment by a psychiatrist or a psychologist; psychosocial treatment = all other types of psychological or social support by the GP, social services, volunteers, etc.

The reasons for the requests for EAS were being through with life (55%), physical decline (55%) and being tired of living (48%) (Table 3).

Course of action of the physician and course of life of the patient

Physicians refused requests for several reasons: the patient did not suffer unbearably and hopelessly (48%) and the patient did not suffer from a severe disease and/or the suffering of the patient was not part of the medical domain (43%) (data not shown).

In 14 out of 29 cases the physician considered one or more types of treatment (Table 4). Four patients refused all the suggested treatments, three patients refused some of the suggested treatments, but received one or more other treatments.

Ten patients received one or more treatments. After receiving treatment, three of these patients no longer wanted EAS. Of these three patients, one was treated with antidepressant medication, the second received psychosocial support and the third was hospitalized and treated for shortness of breath, and also received psychiatric and psychosocial support. These patients were persuaded to moderate their request for EAS but they still wanted to be able to end their life in due time if they so wished. In two cases the request was withdrawn completely, in one case this happened after treatment with painkillers and in the other case after treatment of a medical problem in combination with antidepressant medication. The other five patients maintained their explicit request for EAS after they had received treatment. One of these patients went to another physician who granted the request for EAS.

Nineteen patients who did not receive any treatment persisted in their request for EAS and in four cases the request for EAS was granted. Five patients took their own life after their request was denied; three hanged themselves and two died of self-starvation, one of them at the advice of the physician. The remaining 10 patients persisted in their request for EAS. At the time of the study four had died of natural causes.

To give an impression of the patients described in this article, a combined description of the characteristics of several patients is given as an example in the following 'Case report'.

Case report

A woman, 81 years old, asked her GP if he had a pill for her to end her life. The GP had known her for a

long time and the question did not really surprise him. Since her husband died 15 years ago, she had lived alone. Since then, people around her had died and she was the last one of her generation alive in her family. She had good relationships with her three sons, even though she often complained that they did not spend enough time with her. She had a visual and a hearing impairment and she had difficulty walking, but she was well taken care of in sheltered accommodation. When her GP asked her why she wanted to end her life, she said that she was weary of life. She felt that she was physically declining and she did not want to live to see how she deteriorated further. She had seen members of her family developing dementia and she did not want that to happen to her. She had no prospects and felt lonely most of the time. She had drawn up the balance and decided that she was better off dead. When her GP explained why he could not provide a pill she seemed to accept the situation. After that they had several conversations concerning the subject. She seemed to accept her predicament, but she said regularly that she would rather be dead and that she hoped her GP would change his mind.

More detailed descriptions of similar patients have recently been published (De Burlet & Hazenberg, 2003; Calman, 2004).

DISCUSSION

One limitation of this study is that it is a retrospective interview study. Therefore, some doubts may arise with regard to validity, even though the physicians remembered these patients very well, probably due to the peculiarity of the requests for EAS, which were from older people who did not have a severe disease. Another limitation of this study is that only physicians were interviewed. To obtain a complete picture of the reasons involved and the line of thought of patients leading to their wish to die, they too should be included in a study. Furthermore, only a small number of cases have been described in detail in the interviews, due to the fact that such requests are a rare occurrence. However, we think that because of the high response rate and the guaranteed anonymity, this study provides an initial reliable insight into requests for EAS in the absence of a severe disease. Interviewing people with a wish to die might be a logical next step in further research.

It is estimated that each year 400 people in The Netherlands request EAS because they are 'weary of life'. These people mainly suffer from the physical ailments and social problems that are frequently encountered in older age. They seem to have a crude but rational deliberation: after a long life they are now deteriorating physically and they feel that they have no role left in life. The question remains, however, as to why they want to actively intervene instead of waiting for time to take its course. It seems that circumstances such as the loss of a partner, increasing isolation due to the death of people around them, and physical ailments can make everyday life such a negative experience that it can turn being 'weary of life' into a reason to actively wish to die.

It could be said that all the patients in our study suffered from *depressive symptoms*, since they all had a wish to die. In The Netherlands it is widely accepted that it is possible for a person to have a death wish without suffering from a *clinical depression*. Of course, especially in other countries, not everybody agrees with this. We cannot rule out the possibility that some of the patients in our study did suffer from a clinical depression, even though this was not diagnosed by the participating physicians. We realize that differentiation between depressive symptoms and a clinical depression is rather complicated, especially in older people, and that a clinical depression is often not detected by physicians. However, there is probably a much smaller chance of missing such a diagnosis in a patient who makes an explicit request for EAS. In the first place, because the wish to die is made explicit by the patient and can, therefore, not be overlooked, and also because it is normal procedure when dealing with requests for EAS to exclude the possibility of a depression, because the competency of a patient with a depression can be doubted, and treatment may be possible.

Most physicians in The Netherlands refuse requests for EAS in the absence of a severe disease, mainly because they do not consider these patients to be suffering unbearably or hopelessly. Requests that were granted had all been granted longer than 2 years ago, so we have found no evidence of a 'slippery slope' of EAS widening its scope in practice to patients who are not severely ill, even though the existence of a debate about EAS for patients who are not severely ill might, in itself, be considered to be an indication of a slippery slope.

Physicians apparently do not always consider a request for EAS as an opportunity to suggest certain treatments or other interventions that could make life more bearable or satisfactory for these patients. Another study also showed that physicians had difficulty addressing patients' existential suffering (Kohlwes *et al.* 2001). The responsibility and expertise of a physician in treating these patients is debatable, since it can be questioned to what extent the problems of these patients pertain to the medical domain (Smith, 2001; Leibovici & Lievre, 2002). The Royal Dutch Medical Association has established a committee that addresses this question. However, whether or not these problems pertain to the medical domain, these patients turn to a physician to ask for help.

Little is known about the possibilities for treatment for these patients: can they be helped, in what way, and by whom? While much has been published concerning suicide in the elderly, studies about death wishes are virtually non-existent. This is remarkable, since 9·5% of people aged 65 years and over reported death and/or suicidal ideation or intention in the past year, while only 0·14% had actually attempted suicide (Scocco & De Leo, 2002).

However, the fact that so little is known about the possibility of treating people who have a wish to die, does not dismiss them as being patients who can not be treated at all by a physician. In two thirds of the cases in this study the physicians did not treat the patient and in half of the cases treatment was not even considered. Should this be seen as unwarranted 'therapeutic nihilism', or is there really nothing that a physician can do in such situations? The fact is, that in this study the request was withdrawn or became less explicit after treatment in five cases, but this never happened when no treatment was given. Although the problems of these patients may seem to be inevitable, because they are inherent to ageing and determined by societal values, the significance of physical discomforts should not be underestimated as a reason underlying a wish to die. Interventions mitigated some of the problems, such as pain, visual and hearing impairment, individual physical discomforts and depression, support in taking up activities and social contacts was also helpful in some cases. Maybe not all of these aspects of treatment seem typical of the responsibilities of a physician, but at least observing the necessity of treatment and referral certainly are.

In our opinion, however small the odds of recovery appear to be, treatment should always be considered. Therefore, research is needed into practical approaches for physicians, not only to prevent suicide, but also to make life more bearable and satisfactory for elderly people who wish to die.

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DECLARATION OF INTEREST

None.

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